

## **FASD Education Framework**

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### **Scope of Work**

Fetal Alcohol Spectrum Disorders (FASDs) affect a diverse range of systems across the State of Alaska. The need to train stakeholders and key participants within these systems in ways to appropriately respond to individuals and families with FASDs is paramount to reducing caregiver frustration and increasing positive outcomes for families and individuals. Training regarding FASDs in the State of Alaska is currently reliant on [curriculum](#) developed nearly 20 years ago that is in need of updating.

The goal of this project is to prepare and develop a comprehensive framework for FASD educational needs in Alaska that can take advantage of updated research and technologies and better serve the diverse needs of the state. The project began by engaging stakeholders across the state in an informal survey regarding training resources available in specific geographical locations, particular focus and targeted audience. In addition, questions regarding use of current trainings in the state were sent to the last available comprehensive list of trainers (updated in 2015). The survey allowed engagement of stakeholders in the FASD community and provided important insights and discussion points for the key educator meeting to understand the perspectives of the broader community.

The project culminated in a 2-day meeting at which key educators from the FASD community came together to review survey results and identify training goals, core themes and key outcomes for training in the state of Alaska. The group took time to identify key goals for focus within the FASD community as well as to participate in a robust discussion on how to identify best practices within the emerging field of FASD expertise.

### **Historical Perspective**

The State of Alaska developed FASD 101 for service providers, families and community members living and working with individuals with FASD. Following the development of FASD 101, FASD 201 was created to fill the need for additional training and resources for those more closely involved with individuals who experience FASD. FASD Into Action, a curriculum developed in Oregon, was later supported by the state of Alaska as an additional in-depth training. All of these trainings rely on a network of “trained trainers” the number of which has diminished over the years. Although FASD 101 was updated in 2015, due to the emerging research in this field it is already in need of updating.

The Binkley Act mandates that all teachers in Alaska receive training on FASD when they are hired. To meet this need, the Department of Education and Early Development has developed

an [online training for educators](#). This training is in regular use for teachers newly hired to the district.

FASD 101 Training of Trainers was last held in 2015. Survey results indicate that this curriculum is still in use across the state. FASD 201 is still used, though not as frequently. [FASD Into Action](#) is offered by a limited number of trainers in the state.

### **Survey Results**

Two separate surveys were created and distributed for this project. The first targeted FASD trainers across the state. The survey was sent to a list of 93 trainers that was last updated in 2015. The survey was also distributed to the FASD community via the Alaska FASD Partnership lists as well as the Governor's Council list and individual lists that target particular communities. Of the 93 trainers who were sent the survey (many emails were returned), 24 responded. Of those 24, 18 reported that they are still training in the state of Alaska. Those 18 reported to be training in the following areas:

Foster care: 5  
Adoption: 6  
Medical: 6  
Caregivers: 7  
Mental Health: 8  
Education: 10  
Legal/Incarceration: 2  
Other (ministry/community): 2

Trainers reported that the content of their currently used trainings overwhelmingly focuses on general information, effects on the brain, FASD and trauma, and on strategies for working with individuals. Less (45%) of individuals surveyed reported focus on prevention.

The community audiences for which trainings are geared had the most focus in education and mental health. The medical and caregiver communities were targeted second, and foster care and adoption communities were third in frequency. Less frequently targeted communities were reported to be the legal and incarceration communities.

More than half of respondents reported that their trainings lasted between one and two hours. About 30% reported their training usually spanned about half a day, and only 10% reported offering full day or multi day presentations.

Fifteen of 18 trainers reported that they currently use existing curriculum, with most (10) reporting that they use FASD 101. Other existing curriculum include FASD Into Action, FASD 201, 8 Magic Keys and Centers for Disease Control. Eighty percent of those surveyed reported they maintain their own materials.

When asked to comment on training needs in the state, comment themes included (from more frequent to less frequent):

- Broad reach of training
- Consistency
- More FASD Into Action
- Credentialing
- Money/Funding/Resources
- Personal Perspectives

The second survey targeted stakeholders across the state. This list was also distributed to outreach lists from the Alaska FASD Partnership, the Governor's Council, and Anchorage, Fairbanks and other regions' community stakeholder lists. Respondents included 143 individuals from the Far North, Southcentral, Southeast, Southwest and Interior regions. These included individuals from across systems including foster parents, teachers, therapists/counselors, case managers, direct support providers, behavioral health aides, individuals who experience FASD and others.

Most stakeholders (63%) reported they felt competent in their level of knowledge about FASDs, but were still learning. Only 5% reported having no experience with FASD, which would be expected given distribution domains (mainly individuals who are somehow connected to the FASD community). Additionally, nearly 75% reported having participated in FASD training of some kind, and 75% of those reported that the training they did receive was helpful.

Nearly 70% of respondents reported that a combination of online and in person trainings are most effective. Almost 50% reported wanting more conference sessions available at existing professional conferences.

Interestingly, although FASD trainers reported training the most in the field of education, stakeholders overwhelmingly reported wanting more help in schools with IEPs and more training for educators. In general, respondents also asked for more training in general and training that is broader in geographic reach.

The chart below shows trainings that are reported to be currently used in the state and the last year they were updated.

Training	Audiences	Last updated	Currently used?
FASD 101	General	2009	yes
FASD 201	Providers/Families	2005	yes
FASD Into Action	Providers/Caregivers	2015	yes
8 Magic Keys			yes
Centers for Disease Control	Medical Providers	2018	Yes
DEED	Teachers	2016?	Yes
<u>Whitecrow Village</u>	Caregivers	2019	Yes
ACRF Self Study	Resource Families	varies	Yes

## FASD Key Informants Meeting

**Facilitator:** Christian Muntean, Vantage Consulting

**Attendees:** Cheri Scott, FASD Educator and Advocate

Hope Finkelstein, State of Alaska FASD Program Manager

Jenn Wagaman, Alaska Center for Children and Adults

Teri Tibbet, Alaska Mental Health Board

Alexandra Edwards, University of Alaska Anchorage, Center for Behavioral Health Research and Services

Jeanne Gerhardt-Cyrus, Kobuk Valley Consulting

Marilyn Pierce-Bulger, FASDx Services

Aileen McGinnis, Alaska Center for Resource Families

Michael Baldwin, Alaska Mental Health Trust

Tami Eller, Alaska Child and Family

Erika Mary Madsen, Alaska Center for FASD

Deb Evenson, Fetal Alcohol Consultation and Training Services

Monica Charles, State of Alaska Guardian Ad Litem

## Meeting Outcomes:

The group's two-day meeting culminated in the following recommendations for an educational framework in Alaska:

Training should meet these core outcomes:

- Affected individuals and families live successful lives in their chosen communities.
- There are informed and engaged statewide communities.
- There is a broad understanding that FASD is systemic (beyond just focusing on pregnant women).

- Champions are trained and able to advocate for change within their own systems.

Training should be:

- Research-based and current
- Have a coordinating hub
- Accessible and relevant to all Alaskans
- Informed by trained experts in the systems that are receiving training
- Include lived experience from individuals who experience FASDs
- Use existing/emerging tech for delivery
- Be adaptable and customizable

Core content should include:

- Identification and referral for diagnosis
- Strategies that are hands on and brain-based
- Address stigma
- Etiology, effects on behavior and cognition, understanding of brain-based disabilities
- Advocacy (how do systems change?)
- Support resources for audiences (Where to go for more information)

Additional goals for the community:

- How do we identify and grow the next generation of advocates and experts?
- How do we increase the exchange of knowledge between urban and rural communities?
- How do we develop support systems?
  - Local
  - Regional
  - Statewide
- How do we track data?
- How do we increase rural access and create equity?

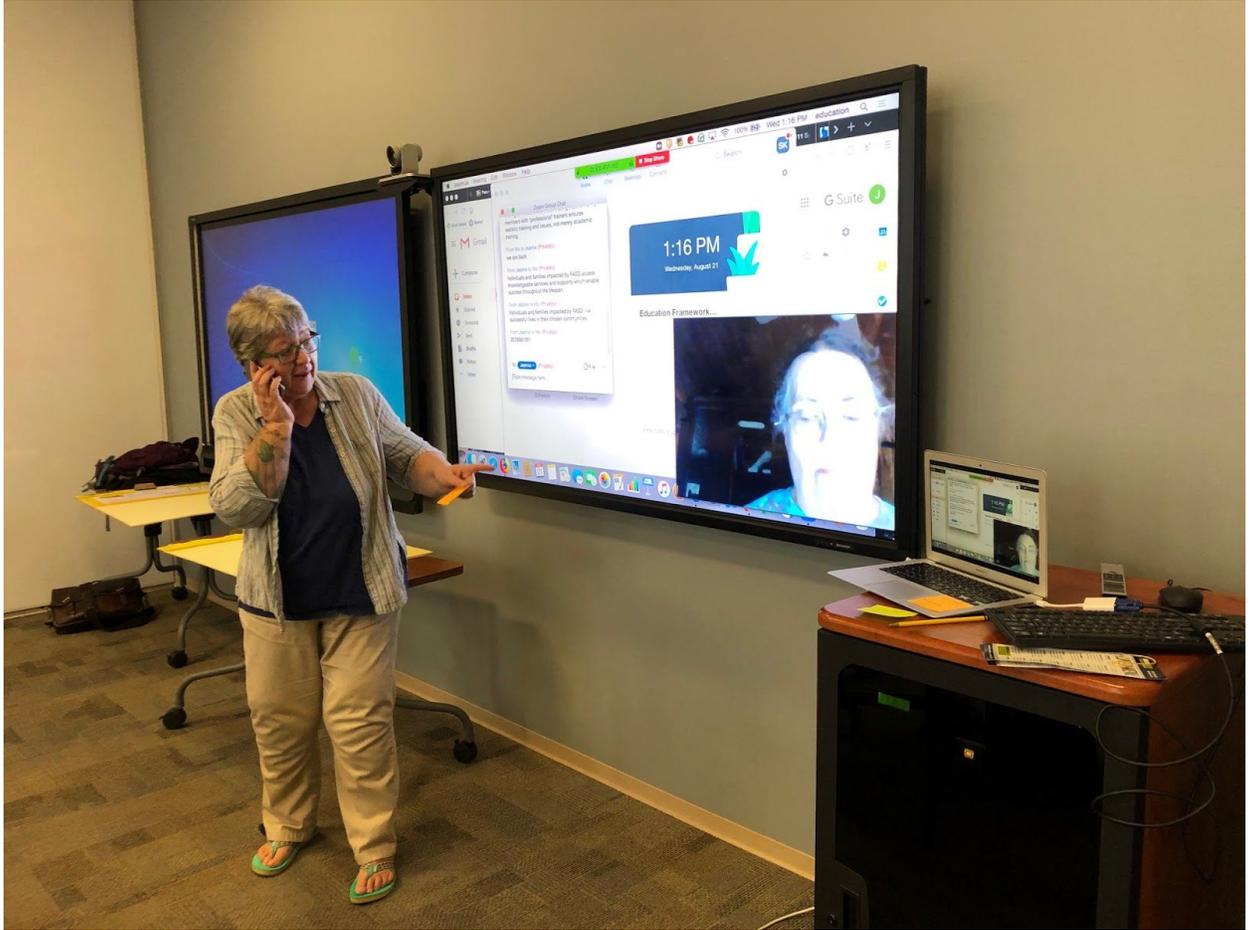
## **Next Steps**

Based on the outcomes of this meeting, we recommend the following steps:

1. Conduct an updated Knowledge, Attitudes Behaviors and Beliefs survey across the state of Alaska. A survey such as this has not been conducted in the state for over 15 years, and significant changes have taken place since that time. The information gathered will be useful in informing the above goals for training.
2. Establish an FASD Training Advisory Board through which materials can be easily vetted electronically, based on a rubric system using the guidelines established by this advisory group. Once materials are vetted, provide these materials to the public or to trainers.
3. Consider implementation and design of a “pre-training” online training that can be provided to those seeking information about FASDs, but who have limited time, or that can be utilized by current trainers as a pre-training resource or supplemental module. House this training on the state website along with resources for trainers.



FASD Key Informants participants gather in Anchorage.



FASD Advocates Cheri Scott and Jeanne Gerhardt Cyrus participate in a brainstorming exercise at the Key Informant Meeting.



Teri Tibbet and Deb Evenson discuss educational goals and FASD at the Key Informant meeting.



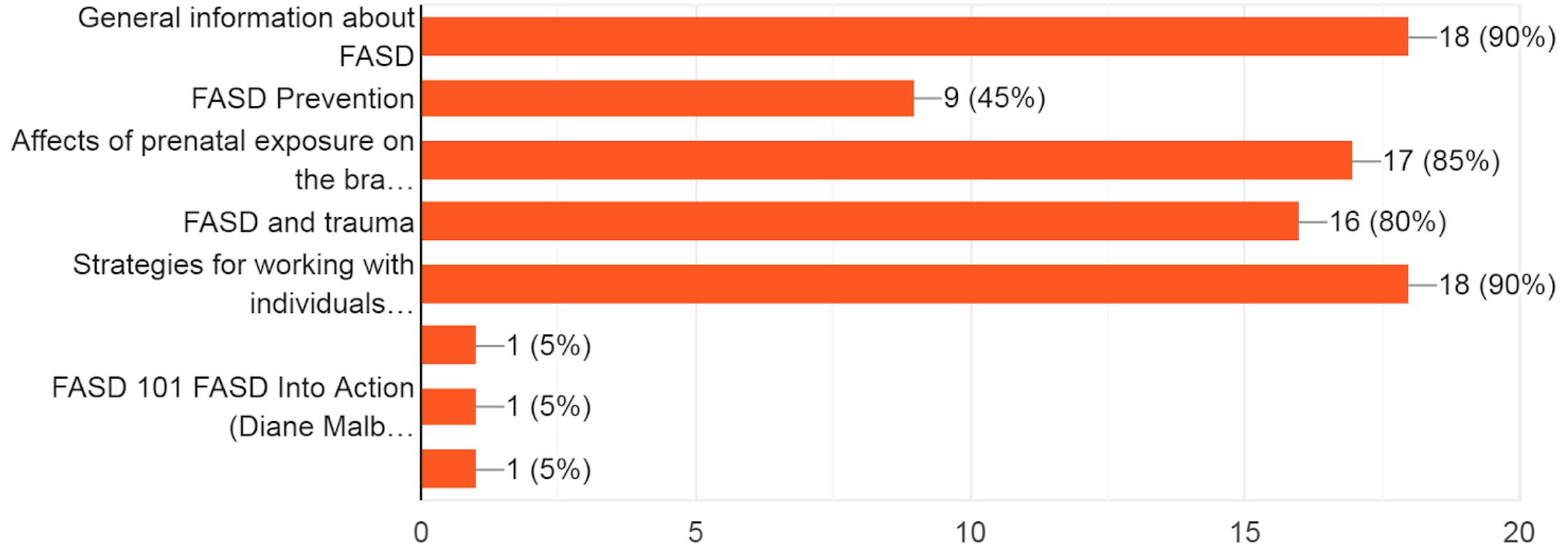
# Who is training?

A list of 93 trainers from 2015 was surveyed (in addition to outreach to others via forwards and lists), 24 responded. Of those, 18 reported they are currently training. Those 18 reported they are reaching the following audiences:

Foster care:	5
Adoption:	6
Medical:	6
Caregivers:	7
Mental Health:	8
Education:	10
Legal/Incarceration:	2
Other (ministry/community):	2

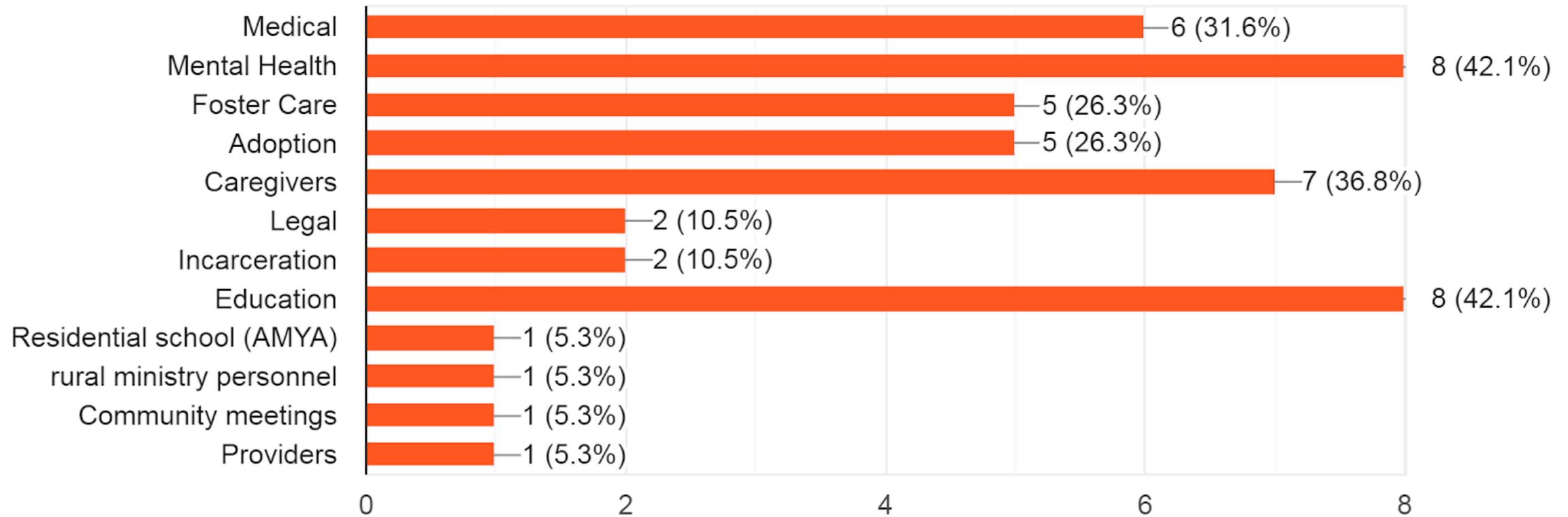
# What is the content of your training? (check all that apply)

20 responses



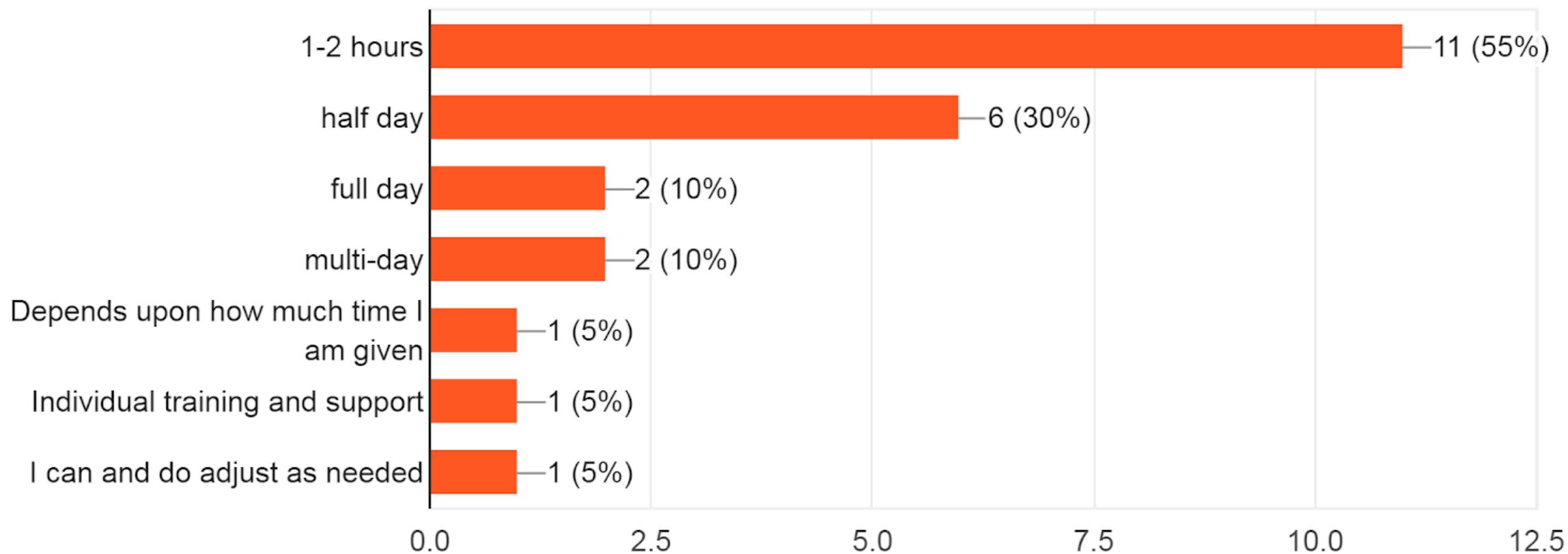
# If yes, what audiences are your trainings usually geared toward? (choose all that apply)

19 responses



# What is the typical length of your training?

20 responses



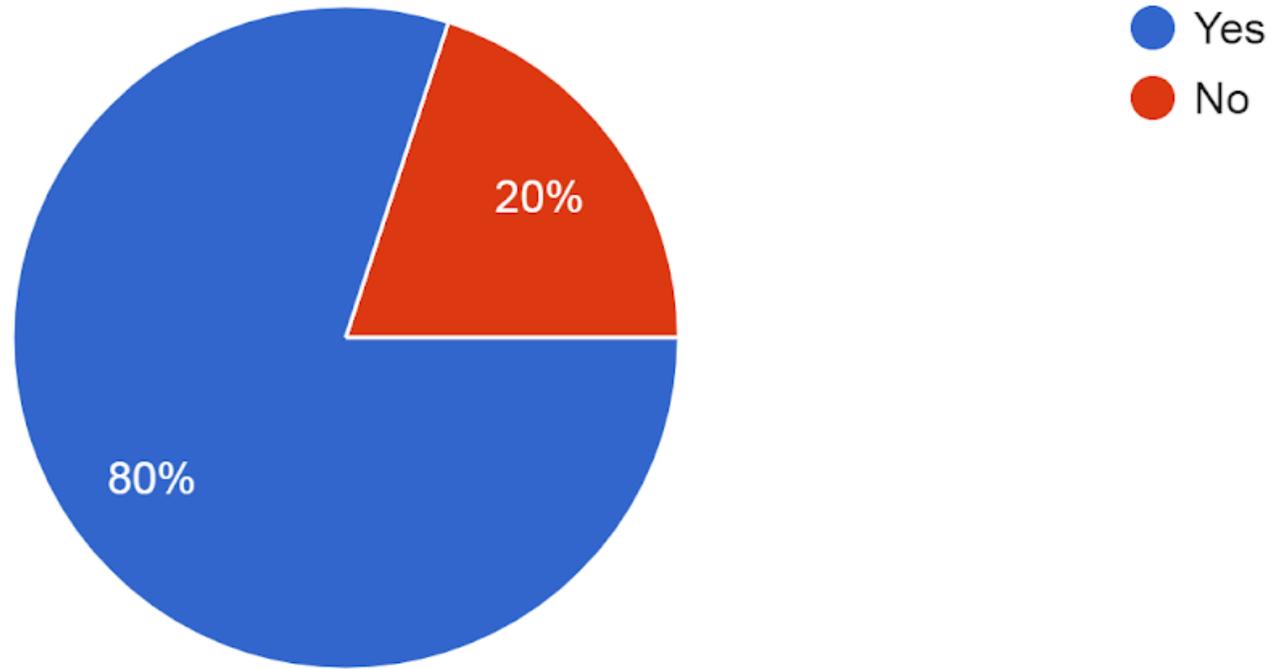
# What curriculum are we using?

15 of 18 trainers report using existing curriculum

FASD 101	10
FASD Into Action	4
FASD 201	4
8 Magic Keys	2
CDC	1

# Do you maintain your own materials for trainings that you have developed?

20 responses



# What do we think is missing?

Themes from the comments:

Broad reach of training, we need to reach  
more people (many people said this)

Consistency

More FASD Into Action

Credentialing

Money/Funding/Resources

Personal Perspectives

Brain break...

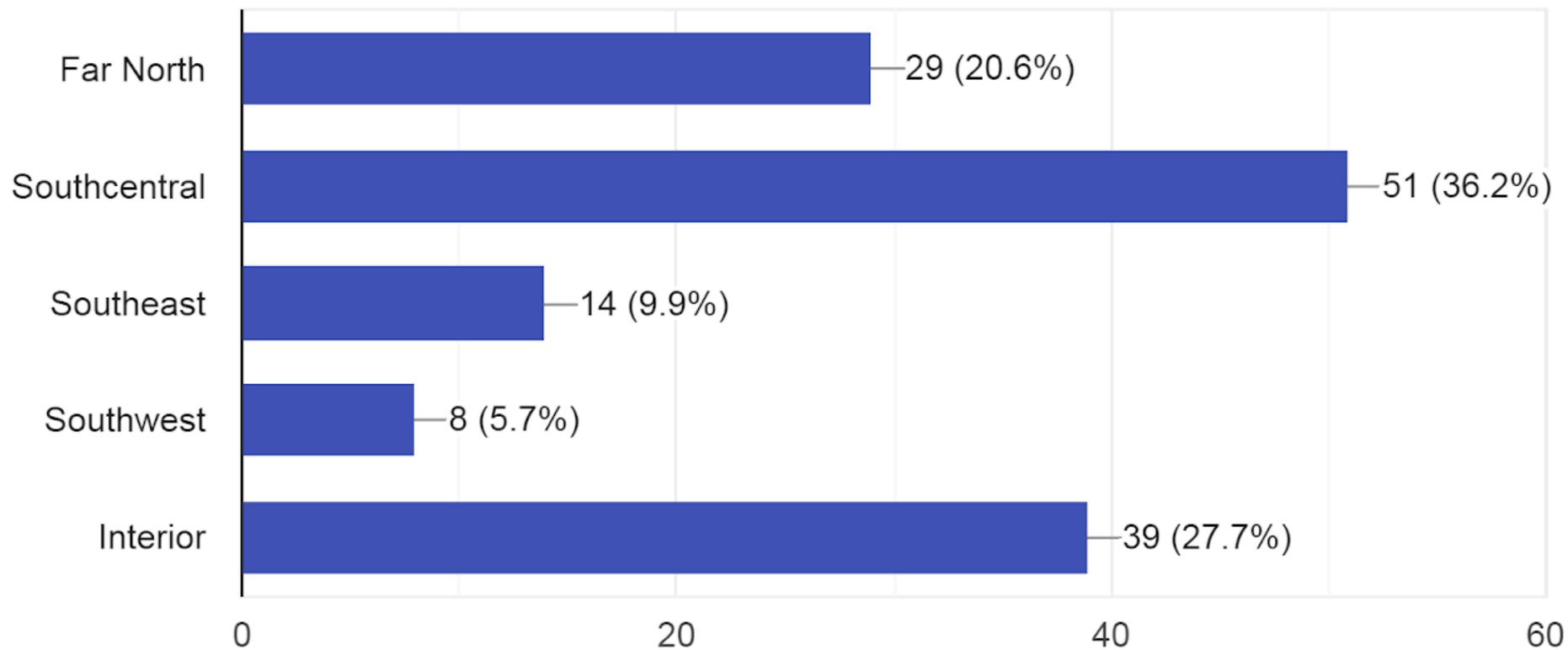


# Stakeholders

Distributed to stakeholders across the state via Governor's Council list and outreach lists from Anchorage, Fairbanks and other regions. 143 people responded with respondents from each region of Alaska.

# What region of Alaska do you live?

141 responses

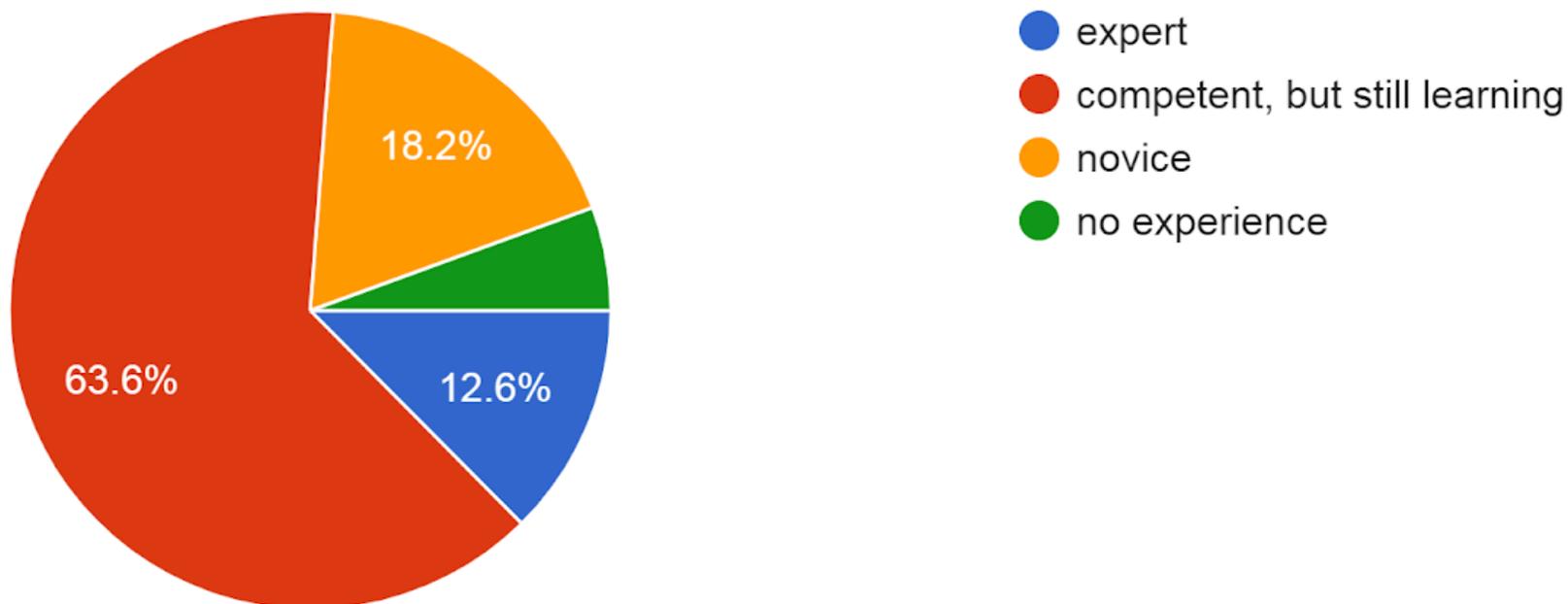


# Respondents

- Foster parents (11)
- Parent/caregivers (46)
- Teachers (13)
- Therapists/Counselors (19)
- Case Managers (9)
- Direct Service Providers (14)
- Vocational Support (3)
- Legal Services (3)
- Behavioral Health Aides (4)
- Nurses
- Diagnostic Team Coordinators
- ICWA
- Physicians
- Diagnosed Individuals
- Health Aides
- OCS workers

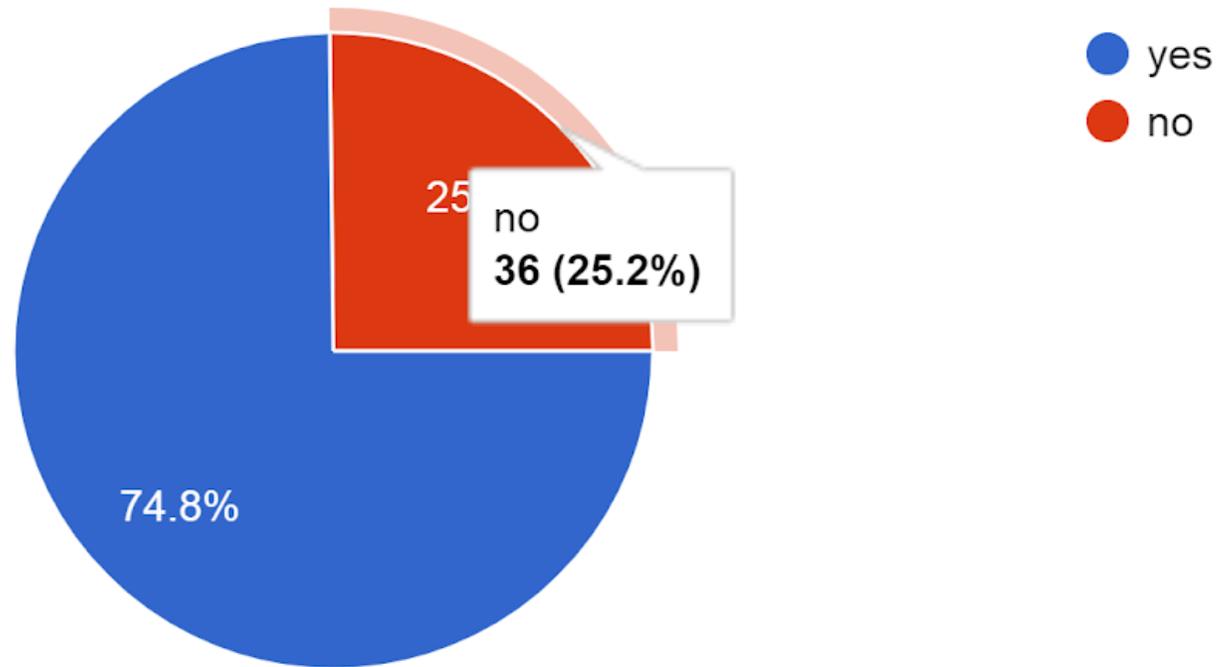
# What is your level of knowledge is regarding fetal alcohol syndrome and fetal alcohol spectrum disorders?

143 responses



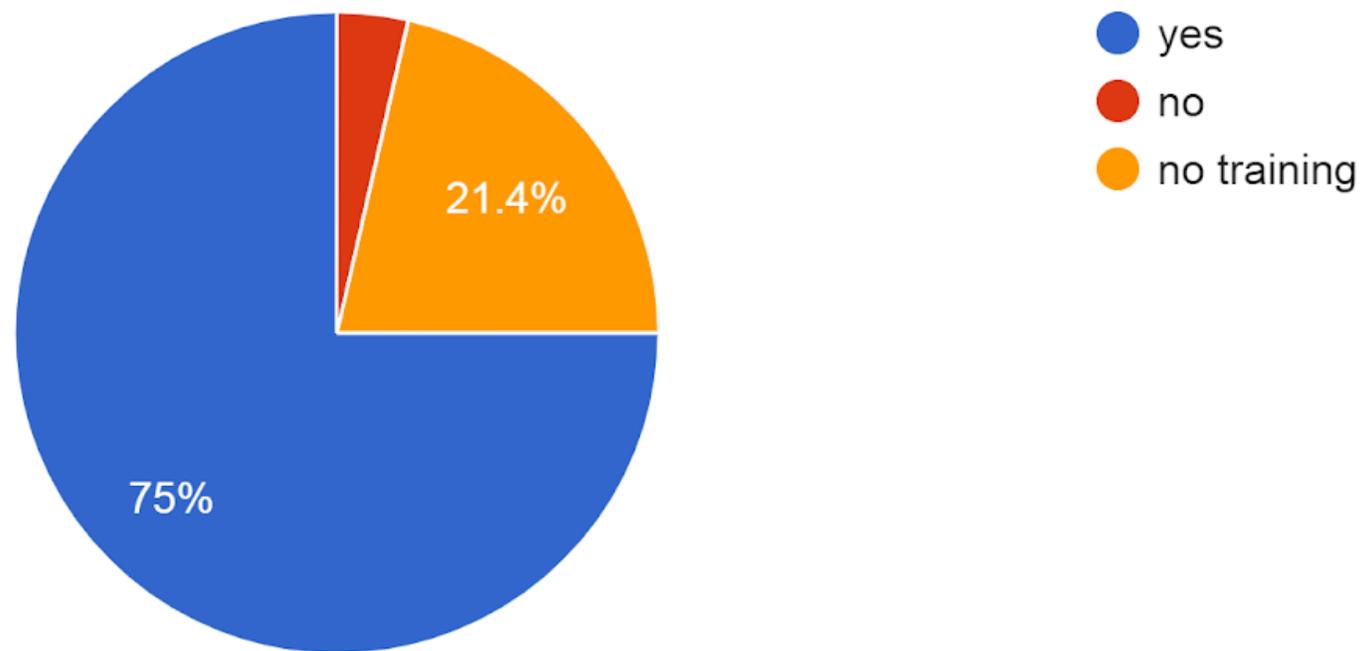
# Have you participated in fetal alcohol syndrome or fetal alcohol spectrum disorders training?

143 responses



# Do you think the training you received has helped you work more effectively with those experiencing FASD?

140 responses



I can't remember most of the training. It was mandatory and more about the process and brain science than strategies for working with students/families (this was when I worked for the school district). Now I work in prevention and there is SO MUCH STIGMA, that it seems like even those working in prevention don't know how to have the conversation. There has been some progress made, but it's just not something that people are talking about. And it's not being prioritized.

I'd really like training that connects FASD and other exposures with issues of toxic or traumatic stress and the training level directed at mental health therapists and masters level interventionists of all kinds (PT, SLP, OT, nurses, etc)

It has helped me but we struggle to get everyone else in our support system onboard.

just to clarify, I've had the parent training but could really benefit from more training. My kiddo was already well into teens before diagnosis so my understanding has improved but I could have benefited from training a whole lot earlier

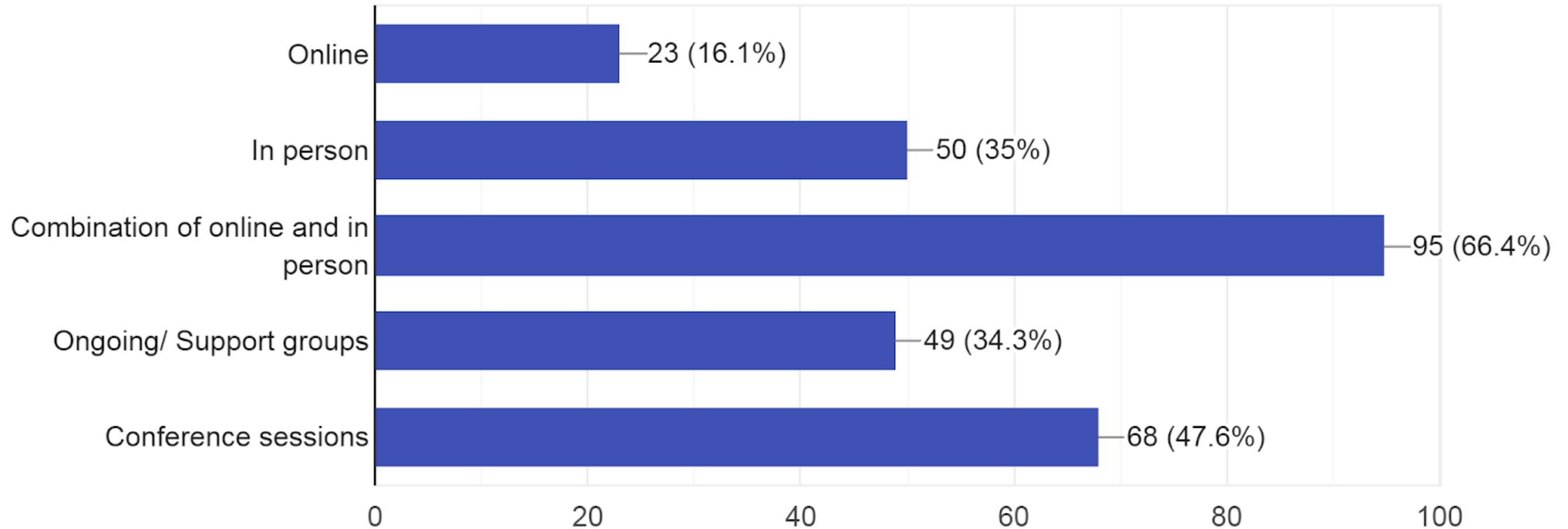
However, the most effective training I have had is living it and living with a spouse with ADHD - figuring out the strategies each of us need to get our needs met in a relationship, where there is very little help or knowledge and much misunderstanding and well-meant misguidance from therapists, etc.

My children keep moving the goal posts

So broad. It seems like having a consultant to help with individual cases is most needed.

# What type of training do you think would be most accessible and effective for you and others in your field?

143 responses



# What do we want in the future?

Themes from the comments:

Help in schools with IEPs and with  
Educators (many people said this)

More training

Broader geographic access and frequency

Training for foster parents and caregivers

Information on how to get services, especially for youth

More Into Action or hands on trainings

Information for rural communities



MIDNIGHT OIL PHOTOGRAPHY  
*Sacha Lages*

# Training needs hierarchy

expertise

certifications

hands on skills

foundational knowledge

# Current Trainings in Alaska

Training	Audiences	Last updated	Currently used?
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# Level of Commitment

## Trainings

- FASD 101/201
- FASD Into Action
- 8 Magic Keys
- CDC



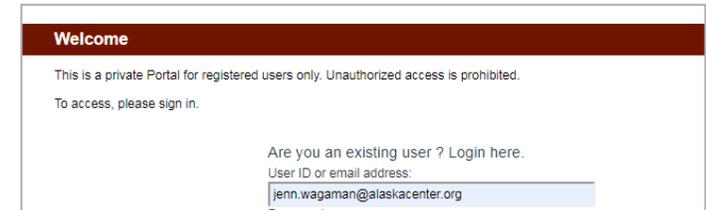
- Professional certifications
- University classes
- Research
- Conference presentations

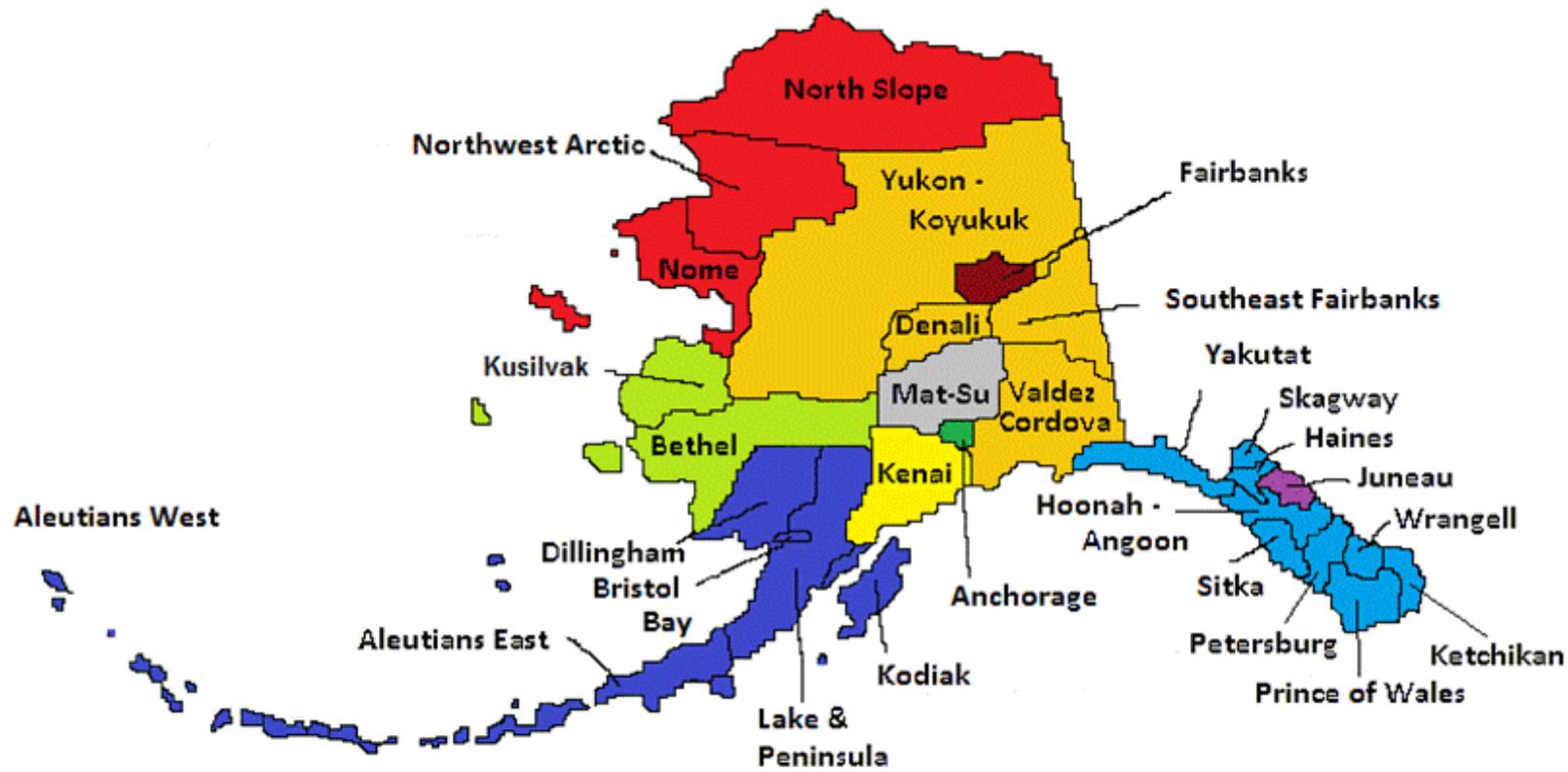
# Advanced training

- University of Washington online class/clinic visits
- Vancouver conferences
- MOFAS Conference
- UAF EDSE/PSY 448 and 648

# What are other folks doing?

- CanFASD
- Trust Training Cooperative
- School District Trainings
- Individual Trainers
- CDC (for medical professionals)
- Whitecrow Village model
- Neurobehavioral models
- ACES trainings





**Behavioral Health Regions**

- |   |   |   |   |  |
|---|---|---|---|--|
| <span style="display: inline-block; width: 15px; height: 15px; background-color: green; border: 1px solid black;"></span> Anchorage   | <span style="display: inline-block; width: 15px; height: 15px; background-color: purple; border: 1px solid black;"></span> Juneau | <span style="display: inline-block; width: 15px; height: 15px; background-color: grey; border: 1px solid black;"></span> Mat-Su   | <span style="display: inline-block; width: 15px; height: 15px; background-color: yellow; border: 1px solid black;"></span> Interior | <span style="display: inline-block; width: 15px; height: 15px; background-color: lightgreen; border: 1px solid black;"></span> Y-K Delta |
| <span style="display: inline-block; width: 15px; height: 15px; background-color: darkred; border: 1px solid black;"></span> Fairbanks | <span style="display: inline-block; width: 15px; height: 15px; background-color: yellow; border: 1px solid black;"></span> Kenai  | <span style="display: inline-block; width: 15px; height: 15px; background-color: red; border: 1px solid black;"></span> Northwest | <span style="display: inline-block; width: 15px; height: 15px; background-color: blue; border: 1px solid black;"></span> Southwest  | <span style="display: inline-block; width: 15px; height: 15px; background-color: cyan; border: 1px solid black;"></span> Southeast       |

# EDUCATION

VERSUS

# TRAINING

Acquisition of knowledge through a process of receiving or giving systematic instruction

Action of teaching or learning practical skills or type of behavior

Students learn theories

Students learn how to apply theories in practice

Academic

Professional or vocational

Necessary in order to complete a training

Cannot be received without a basic education.